

Financing end-of-life care in the USA

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This paper offers an overview of how end-of-life care is currently financed in the USA. It discusses the limitations of the current system, as well as certain population and disease trends that lead us to recommend how financing should be restructured so that optimal end-of-life care is available for the entire population.

CURRENT FINANCING

We do not know precisely how much is currently spent on end-of-life care in the USA. According to one estimate, end-of-life care accounts for about 10–12% of all healthcare spending¹. Annual expenditures for hospice and home care—two healthcare segments that are closely involved in the provision of end-of-life care—are about \$3.5 billion and \$29 billion, respectively².

Medicare's influential role

Medicare, the largest health insurance plan in the USA, is highly influential in end-of-life care because of the large number of Medicare beneficiaries who die each year. Of the 2.3 million people who died in 1997, 80% were Medicare beneficiaries at the time of death³. Of that 80%, one-fifth were also eligible for Medicaid (the 'dual eligible').

According to a report from the Medicare Payment Advisory Commission (MedPAC), about a quarter of the total Medicare budget is spent on services for beneficiaries in their last year of life^{3,4}, 40% of it on the last 30 days⁵. In 1997 Medicare paid an average of about \$26 000 per person in the last year of life, or six times the cost for survivors³. The relation between costs for those in the last year and those for survivors has been remarkably stable; in 1988 it was seven to one⁵. The cost of end-of-life care for people age 85 and over was reported to be one-third lower than that for people aged 65–75³. One explanation for the stability of Medicare's end-of-life costs is that more people are dying at older ages after lengthy chronic illnesses and long periods of functional decline. During this extended period they may receive little in the way of end-of-life services or support.

Site of death is another factor that accounts for variation in end-of-life costs. A 1993 study showed that 44% of all deaths among Medicare beneficiaries occurred in hospitals³. Medicare costs for beneficiaries who died in a hospital inpatient setting were twice those for beneficiaries who died in other settings (e.g. their homes)⁴. The likelihood of dying in hospital in the USA depends not on patient preference but on the number of hospital beds and physicians per head, which varies geographically⁶. For Medicare beneficiaries in some western and north-western States, the chance of dying in an inpatient hospital setting is as low as 20%, compared with more than 50% for those in some southern and eastern States⁷. The site of death for Medicare beneficiaries also correlates with hospice use. For Medicare beneficiaries who used some type of hospice service, 68% died in their homes compared with only 16% of those who did not use hospice³.

Economic burden

Insurance, whether public or private, does not cover all end-of-life costs—the cost of informal caregiving, for example. As a conservative estimate, all informal caregiving in the USA (of which end-of-life care would be a sizeable part) is valued at \$196 billion or 18% of total national healthcare spending⁸. This figure is based primarily on lost wages and social security payments. One study showed that, for patients needing substantial care, 10% of household income was spent on healthcare; families had to take out a loan or second mortgage, spend savings, or take an additional job to cover these costs⁹. The economic burdens of end-of-life caregiving are complicated by the many social and psychological consequences of caregiving. Caregivers of patients with high needs were more likely to have depressive symptoms and to report that caregiving interfered with their lives⁹. In addition, caregivers often have little knowledge of how to deal with insurance companies, and feel overburdened and alone.

Hospice care

Hospice care, often covered by Medicare's hospice benefit, provides end-of-life care to a limited number of patients who are in their last six months of life. Most hospice care is provided on an outpatient basis, with routine home care the most common service¹⁰. The primary diagnosis of 63% of all hospice users includes at least one type of cancer, while

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the total number having some type of cancer is even greater¹⁰; 45% of all cancer patients use hospice³.

Hospice use is on the rise. From 1994 to 1998 hospice use by Medicare decedents increased from 11% to 19%³. From 1998 to 1999, total hospice use increased almost 30% from 540 000 to 700 000 people¹¹. The number of hospices has also increased, from about 1000 in 1991 to more than 2200 Medicare certified hospices in 1998³.

Despite the growing number of hospices and of people who need end-of-life care, hospice revenues and margins have dropped. One reason is that lengths of stay remain low, though they are increasing: from 1988 to 1999, the median stay increased from 25 to 29 days¹¹. In general, hospices incur a financial loss when a patient stays less than one to two weeks; and one sample of hospice enrollees from 1996 showed that 15.6% died within seven days of admission¹².

Hospice spending accounted for 1% of total Medicare spending and only about 0.1% of total Medicaid spending^{4,13}. Medicare covers about two-thirds of all hospice costs¹¹, the remainder coming from private insurance (12%), other (11%), Medicaid (8%) and indigent (4%).

Does hospice care save money? In one study, though total costs were little different, Medicare payments were higher for hospice users than for non-users⁴. This analysis may be skewed by failure to take into account self-selection and diagnosis; one might also argue that hospice care, even if it does cost more, is closer to patient needs and preferences. Other more comprehensive studies, however, have shown savings on Medicare expenditures as high as 68%¹¹.

Key trends affecting end-of-life care

An ageing population, increasing diversity and changing patterns of death and disability are driving demand for changes in the way care is financed as well as how it is provided. Today, 34.8 million Americans are 65 years old or older. This number will more than double by 2050 to about 72.2 million, with a 240% increase in the population age 85-plus¹⁴. Of the 4.3 million Americans who are over age 85, 83% are women, 43% are women who live alone and 17% are women living at or below the poverty level.

In addition there is an increase in the number from ethnic and racial minority groups, of which the Latino population is the fastest growing. From 2000 to 2030, the Latino population is expected to increase by 7%, the African American population by 1% and the Asian/Pacific Islander population by 6%.

Until recently most Americans died soon after the onset of a terminal disease, but today medical developments allow us to die more slowly, from diseases that are often chronic and disabling before death. The prognosis becomes less definite: 'on the day before death, the median prognosis for

patients with heart failure is still a 50% chance to live 6 or more months'¹⁵.

For people over age 65, the average man lives 6 of his last 15 years with a disability and the average women 8 out of her last 19¹⁶. Four of the top five leading causes of death in the USA are now chronic conditions—heart disease, cancer, stroke and cardiopulmonary disease³ (the other top cause is pneumonia). Three-quarters of people who live to age 65 will develop cancer, heart disease, chronic obstructive pulmonary disease, or dementia or will have a stroke in their last year of life¹⁵.

BARRIERS TO END-OF-LIFE CARE

Under the current system, barriers to access or finance mean that people are not informed of their options, forgo care that is necessary or receive care that is not optimal or appropriate.

Financial

All of the trends we have discussed raise issues about the extent to which services covered by Medicare, Medicaid and insurance companies meet the needs of these populations. The first major financial barrier is that most insurance plans do not cover services that are necessary for good-quality end-of-life care. Traditional health insurance favours high-tech/high-cost services and inpatient hospital care, rather than the kind of palliative or custodial care that can often be provided in people's homes (for some States, Medicaid is the one payer that provides significant coverage for these types of supportive care). Another barrier is that coverage is usually linked to a specific site rather than the person. This provides contradictory incentives to providers and often results in lack of coordination and difficult transitions for people who receive care in a variety of settings. Lastly, payment for most services is dictated by a time limit and not by the amount of service that is necessary. In the end, patients are under-served and exhaust benefits for services that would be better used at another time.

Medicare's current benefits, as summarized in Box 1, illustrate these barriers. The services Medicare covers are often inconsistent with the needs of patients who have chronic illnesses and/or are in the last stages of life. Hospice is available only for people who meet specific criteria.

Access

Difficulties created by financial barriers are compounded by the issue of access to end-of-life care, in this instance the Medicare hospice benefit itself. 'Access' encompasses a variety of issues, including awareness of the hospice benefit

Box 1 Medicare benefits

Covered	Not covered
Inpatient/outpatient hospital	Medications (if outpatient)
Surgery and diagnostics	Most palliative care
Routine physician services	Non-skilled home care
Limited skilled home care	(e.g. homemaking, custodial care)
Limited skilled nursing home care	Adaptations for disability
Hospice (if meet criteria)	Most transportation
Ambulance	

(e.g. what types of patients do physicians refer to hospice?), acceptance of the hospice benefit in light of cultural and language issues, acceptance of the Medicare hospice benefit in lieu of the regular Medicare benefit, and the ability to supplement the hospice benefit with other caregivers.

In low-income populations and minorities there are special issues of access. Medicare beneficiaries who die in low-income areas have higher end-of-life costs, are less likely to use hospices and are more likely to die in a hospital than the general population³. African Americans represent only 8% of hospice users, yet make up 13% of the total population¹¹. Language and cultural barriers, possible distrust of the system (e.g. fear of being mistreated or undertreated), and lack of hospice referrals from the medical community may all contribute to this low utilization rate.

Nursing-home residents are another group that tend not to receive hospice care. Only 1% of the nursing-home population is enrolled in hospice, and 70% of nursing homes have no patients enrolled in hospice¹³. This is despite the growing number of people who die in nursing homes (20% of the total population in 1993, up from 18.7% in 1986)¹³. This underutilization results from the emphasis on rehabilitation and restoration that is embedded in both nursing-home philosophy and nursing-home payment systems. The Medicare skilled-nursing-home benefit is specifically designed for short-term rehabilitation patients and not for those who are in the last stages of life. In addition, in most States Medicaid pays hospices directly for any hospice patients who are in nursing homes. The hospices must then pay the nursing homes (for patients' room and board). This process delays payments to the nursing homes, which may already be concerned about narrow margins, and becomes a barrier to hospice services for nursing-home residents.

People with non-cancer diagnoses are also less likely to use hospice, usually because physicians tend not to refer them. Possible explanations are that physicians think hospice services are only for cancer patients, do not think of these patients as 'dying' or simply find the task of prognostication too difficult for non-cancer diagnoses.

The HIV/AIDS population is surprisingly under-represented in hospice. One reason is that many people with HIV/AIDS—who tend to be young—want the option of aggressive and experimental care in addition to hospice services. Medicare's hospice guidelines prohibit this. In addition, the increasing life expectancy and reliance on complex drug regimens often make HIV/AIDS patients ineligible for hospice—either because they do not meet the six-months-to-live criterion or because the cost of the drugs is too high.

HOW CAN WE IMPROVE THE WAY END-OF-LIFE CARE IS FINANCED?

The major strength of our current financing system is that hospice care is a standard benefit included in the Medicare programme and in many commercial insurance plans. Without paying additional premiums, patients can choose hospice and receive palliative care primarily in a home-based setting. Hospice tries to manage a patient's physical, social and spiritual needs, with a strong emphasis on controlling pain and discomfort. Counselling and support is also provided to family members. As a result of this benefit and a raised consciousness about end-of-life care in both the medical community and the consumer population, the number of hospice programmes is increasing and hospice is now the standard of care for certain groups of patients (e.g. cancer patients).

Despite the growth of hospice programmes, changes in financing are needed if high-quality end-of-life care is to be available to everyone. Currently, limited knowledge about and access to hospice prevents many patients from taking advantage of this option. Many families cannot handle the additional burdens caused by the gaps in hospice coverage (e.g. limited home health aide hours). A serious weakness in our current system is that in most instances patients receive palliative care only at the very end of their life and only if they choose hospice. Finally, many hospices are struggling to achieve long-term financial stability under the current system, and the closing of any hospices would make access an even larger issue.

Incremental changes

Incremental changes in end-of-life financing could be focused on the hospice benefit or on the entire system.

Hospices operate with little or no financial cushion. The increasing burden of drugs is illustrated by the fact that in one New York City hospice medications are reimbursed at \$1.50 per day but the average cost for drugs is \$10–12 per day. One possible remedy would be to develop a payment adjuster or outlier for high-cost patients under the hospice benefit. Payments would be higher for the first and last day of care and for people who required additional amounts of

care (e.g. more drugs, intensive treatments or additional custodial care). This would ensure that hospices remained financially sound even if they cared for a sicker patient population or if patients were being referred to them at the very last and most expensive stages of their illnesses.

To meet the challenges imposed by the changing demographics in America, hospices must become more culturally diverse. They must reach out to under-served ethnic groups and offer care that is culturally sensitive, from multilingual providers. In addition, the hospice benefit should be modified to include the needs of non-cancer patients and nursing-home residents.

In terms of incremental changes to the current system, one option would be to pay hospitals for end-of-life care using a DRG (diagnosis-related group) modifier. This would enable hospitals to sustain comprehensive end-of-life programmes within their institutions.

Another option might be to provide financial incentives to nursing homes to provide end-of-life care. This could be done by creating a special hospice benefit for nursing-home residents, by allowing nursing homes to bill Medicaid directly for residents who are on hospice, or by increasing the payments for patients who are clinically complex, deteriorating and in need of intensive symptom and pain management.

A third option is to create a risk adjuster for Medicare's managed care programme to provide Medicare+Choice plans with an incentive to care for beneficiaries who are very sick and chronically ill. (Current incentives tend to favour the younger, healthier, beneficiaries who need services less frequently.)

Comprehensive system change

Currently, many people who would benefit from hospice care do not get it at all—or get it only in the last weeks or days of their lives. The question remains: must palliative care be restricted to the dying or should it be available to anyone with a progressive debilitating chronic illness that will eventually be fatal?

Comprehensive system change is another way to improve the current system. Under a new system, end-of-life care would be provided on the basis of disease severity and functional disability—not by prognosis. In this way, the most appropriate set of services could be offered at an earlier point in the disease trajectory.

Yet another way to change the financing of end-of-life care would be to change the flow of payments to encourage continuity of care across site and time. Allowing the benefits to follow the patient would ease problems with transitions and give patients a broader range of options.

Finally, a stronger financial emphasis could be placed on supporting family caregiving. Expanded respite benefits and

other services (such as increased training for caregivers, additional custodial services, and expanded transportation services) would relieve some of the caregivers' burdens. They would also provide families with a more realistic option of caring for dying family members at home.

CONCLUSION

Whatever path is chosen, the new financing system needs to include three major elements. First, the system needs to define and measure the essential elements for good-quality end-of-life care. Secondly, the system needs to support patient and family preferences and provide them with the knowledge and tools to make informed decisions; for patients and families to make a real choice, they need to know what their options are. Finally, the goal of the system must be that good end-of-life care is the norm rather than the exception.

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